Ethical Dilemmas in the NICU

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Learning Objectives

• Introduce approaches to ethical decision in the NICU
• Discuss seminal cases in the development of neonatal ethics
• Discuss driving ethical principles for application in neonates
Disclosure

Dr. Cleary has no Conflict of Interest to disclose

Dr. Cleary has no Financial or Scientific disclosures

Dr. Cleary has no Off-Label disclosures.
Scenario #1

http://www.youtube.com/watch?v=w-ShKr3d9E
Senerio #2

- http://www.youtube.com/watch?v=Zp11WL0PVOI
Senerio #3
Ethical approaches
Consequentialist

- Utilitarianism-Jeremy Bentham and John Stuart Mill
  - Act to produce the greatest good for the greatest number.
- Consequentialist approach- the consequences of the action are more important rather than the action itself.
- Big guy in Trolley 2 is a means to an end that maximally benefits the most people.
- Can fail to properly consider interpersonal relationships.
Jeremy Bentham
Present but not voting
Ethical approaches

Motivation

• Immanuel Kant- morality of an act depends on motive from which the act was done.

• Categorical Imperative- duty to respect another as a rational person.

• See persons as end in themselves, not means to an end. Big guy needs to be respected and should not be pushed in front of the trolley.

• Limits on interpersonal relationships-Universal law for similarly situated.
Ethical approaches Duty

Deontological- Duty to act/ rescue
Unique obligations to those closest to us- direct the trolley away from our kin?

<table>
<thead>
<tr>
<th>Remote and low risk (good Samaritan)</th>
<th>Remote and high risk (firefighter)</th>
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<tr>
<td>Close and low risk (food for kids)</td>
<td>Close and high risk (kidney donor)</td>
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Decision-Making
Requires a process
Pure democracy—majority can decide morally unjust decisions
Pure property rights—can do anything with it as long as we own it.

Who?
- Patient?
- Clinicians/Physician?
- Family?
- Society?

What?
- Morally justified decision
Who decides for children?

• http://www.youtube.com/watch?v=yVRv5u36Huw
“Baby B.”: A Paradigm Case in Pre–Baby Doe Neonatal Bioethics

- Baby B. was referred to...[the MD] at the age of 36 hours with duodenal obstruction and signs of Down’s syndrome.
- His young parents had a ten-year-old daughter, and he was the son they had been trying to have for ten years; yet, when they were approached with the operative consent, they hesitated.
- They wanted to know beyond any doubt whether the baby had Down’s syndrome. If so, they wanted time to consider whether or not to permit the surgery to be done.
“Baby B.”: A Paradigm Case in Pre–Baby Doe Neonatal Bioethics

• Within 8 hours a geneticist was able to identify cells containing 47 chromosomes in a bone-marrow sample.

• Over the next three days the infant’s GI tract was decompressed with a NG tube, and he was supported with intravenous fluids while the parents consulted with their ministers, with family physicians in their home community, and with our geneticists.

• At the end of that time, the B’s decided not to permit surgery. The infant died three days later after the withdrawal of supportive therapy.
Two Moral Questions regarding Pediatric Decision-Making

1. Who is morally **authorized** to make decisions on behalf of children (and on what basis)? **PROCEDURAL**

   • 2. What, if any, decisions are morally **obligated**, which are **permitted**, and which are **prohibited**? **SUBSTANTIVE**
1. There are three possible decision-makers: patient, patient’s family, or clinical team.

2. The primary stakeholder, the pediatric patient, is incapable of making decisions.

3. Clinicians’ roles are limited to medical judgments, but decisions about whether a life is “worth” living are fundamentally value judgments.

4. The family is the unit “in and through which the child will live” and their values should hold sway.

5. Thus, while decision-making must be meaningfully shared, families hold *primary* decisional power.
Smith’s Substantive Argument (pp. 40–46)

1. Baby B is a human person. (assumption)
There is no reason to feel guilty about putting a Down’s syndrome baby away, whether it is “put away” in the sense of hidden in a sanitarium or in a more responsible lethal sense. It is sad, yes. Dreadful. But it carries no guilt. True guilt arises only from an offense against a person, and a Down’s is not a person.

1. Baby B is a human person.

2. There is a prima facie prohibition against withholding treatment from human persons.

3. This prohibition (#2) can only be overridden when it is necessary to protect the life of at least one specifiable other person or when the person is “beyond our care.”

4. Neither overriding consideration in #3 is applicable in cases like Baby B.

5. Thus, it is morally prohibited to withhold treatment in cases like Baby B.
Baby Doe: facts of the case

• 31 yo G3P2 with two healthy children
• Meconium stained amniotic fluid.
• Apgars 5 and 7 (1 and 5 mins), BW 2722g
• Classic Down Syndrome facies
  – TE fistula with esophageal atresia,
  – possible aortic coarctation
• Parents refused surgery – were counseled by OB, Pediatrician, others
• Baby given phenobarbital and morphine.
• Parents visited often, held child
• He died on day of life #6
Timeline: Baby Doe controversy

• April 15, 1982: Baby Doe died
• May 18, 1982: DHHS informs health care providers that they could lose funding if they discriminated against the disabled.
• March 1983: Hospitals ordered to post "hotline" number for reports of discrimination.
• March 1983: AAP, NACHRI, and CHNMC brought suit against DHHS
Timeline: Baby Doe controversy

• March 17-April 14: 600 hotline calls.
  – 16 made specific allegations
  – 5 merited investigation.
  – None found to warrant further action.
• April 8, 1983: Hearing in federal court
• April 14, 1983: HHS regulations ruled invalid on procedural grounds.
• July 5, 1983: HHS regulations reissued with time for public comments.
The Triangle . . . Where the conflict begins . . .

Parents

Society/Law

CHILD

Health care
How do we solve these in pediatrics?

Best Interest Standard (BIS)

Harm Principle

Reasonableness
Best Interest Standard (BIS)

• Under the BIS a surrogate decision maker must determine the highest net benefit among available options.

• BIS states that a surrogate is to choose what will best serve the patient’s interests . . . maximally promoting the patient’s good.
What does the “Best” mean to you?

• Many people think that equals “ideal”
  – Does it?
  – Should it?
Harm Principle

1. By refusing to consent are the parents placing their child at significant risk of serious harm?
2. Is the harm imminent, requiring immediate action to prevent it?
3. Is the intervention that has been refused necessary to prevent the serious harm?
4. Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm?
5. Does the intervention that has been refused by the parents not also place the child at significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?
6. Would any other option prevent serious harm to the child in a way that is less intrusive to parental authority and more acceptable to the parents?
7. Can the state intervention be generalized to all other similar situations?
8. Would most parents agree that the state intervention was reasonable?
1. Decision makers use the best available information to assess the incompetent person’s immediate and long-term interests & set as their prima facie duty that option that maximizes the person’s overall benefits and minimizes long-term burdens.

2. Decision makers should make choices for the incompetent person that at least meet a minimum threshold of acceptable care:
   - judged by what others would view as acceptable in the same circumstances
   - doesn’t require the “best” requires a minimum of care
Ethical Principles in consultation

- **Autonomy** - self-directing freedom and especially moral independence

- **Beneficence (golden rule)** - the doing of good; active goodness or kindness
  - Duty to rescue - special case of beneficence

- **Nonmaleficence (silver rule)** - the quality or state of not being harmful.

- **Justice** - the quality of being just; equitableness or moral rightness

- **Quality of life and best interest** - what decision will best serve the patients interest

- **Futility** - ineffectiveness; uselessness.

- **Reasonableness** - judged by what others would view as acceptable in the same circumstances. Doesn’t require the “best”, requires an acceptable minimum of care.
Pick a principle

- Baby girl with anencephaly
- Baby boy with Downs syndrome and DA
- Mom refuses AZT in labor
- Boy with rare metabolic syndrome requires med costing $600,000/year
- 22 0/7 weeks girl delivers in triage. Parents want everything done.
- 13 year old girl declared brain dead - parents want to remain on ventilator.
- HLHS - best center 500 miles away. Excellent center 5 miles away.
Jay is a five-day old boy born at term and without complications.

He presented to the emergency room on day two with lethargy, poor feeding and cyanosis.

He was resuscitated, started on prostaglandins, and diagnosed with hypoplastic left heart syndrome.

After admission to the NICU, the family was informed of the diagnosis, treatment options, and prognosis.

They did not want to seek further treatment, but wanted to go home and give Jay comfort care.

The neonatologist asks for an ethics consult:
What is the question?

• 1. Does the family have the authority to do this?

• 2. Do I need to get a court order for treatment?
Understand the circumstances

- Medical questions:
  - Are there other birth defects?
  - Are other organs damaged?
  - What are the statistics concerning HLHS?
    - Primary treatment is a staged surgical repair. Transplant a limited option.
      - 5 year survival historically 45-60%
      - Best centers have 3 year survival of 70%
      - Long term harder to predict. Some staged repair survivors will need heart transplants, or may die in early 20’s.
      - Heart transplants graft survival at 10 years < 50%.
Understand the circumstances

- Situational information
  - How were the options framed for the family?
  - What type of quality of life should the child and family expect?
  - Are there social or cultural background expectations?
  - What are the family’s motivations
    - resources, other family issues, life experience, family history.
    - Here’s more history...
What are some of the ethical principles involved?

- Parental Authority - who is making the decision?
  - do the parents feel free to make the decision?
  - is the mode of operation for decision making in the Amish community normative and without pressure?
  - will the parent be ostracized by the community if they go against the community interest?
What are some of the ethical principles involved?

- **Beneficience** - what is a morally justifiable decision in baby’s best interest?
  - Quality of life may initially be good, but dwindle as community resources dry up.
  - What if quality of life depends upon equipment powered by electricity - no electricity in Amish communities.
What are some of the ethical principles involved?

- **Justice** - what is equitable and morally right for community?
  - Amish community will have less resources if this family bankrupts the community treasury.
  - Treatment of this child could harm others by limiting resources.
  - Family has had other babies die of CHD- precedent for family and community.
  - Family and community accept the limited life prognosis.
Recommendation

- The ethics committee recommends....
Important Question about Premise #3

Has Smith identified the *only* two justifiable exceptions to the general prohibition against withholding treatment?

- If there are other conditions (e.g., that providing the treatment simply would be too costly to justify) that might also override the general presumption, then the argument (at least as stated) would be unsound.
When Sound Arguments have Troubling Implications

- Sometimes an argument that appears sound at first glance yields *implications* that are implausible or at least difficult to accept.
- In some cases, an implication might be so unacceptable as to constitute a sufficient reason to go back and reject at least one premise in the argument so as to avoid the conclusion.
A Troubling Implication of Smith’s Substantive Argument

“it leads to the salvaging of a very large number of seriously defective children...[whose lives entail] sacrifice and hardship for the child, siblings, and parents.” (p. 45)

- **Smith** → proper response is **not** to reject a sound moral argument, but rather to **consider how the larger macro-level systems for health care payment and delivery and general social support could be restructured** so as to **more justly distribute the burdens** this ethical presumption places on parents.
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